



Ulcerative colitis

Information for people with inflammatory bowel disease

PE-IBD-02

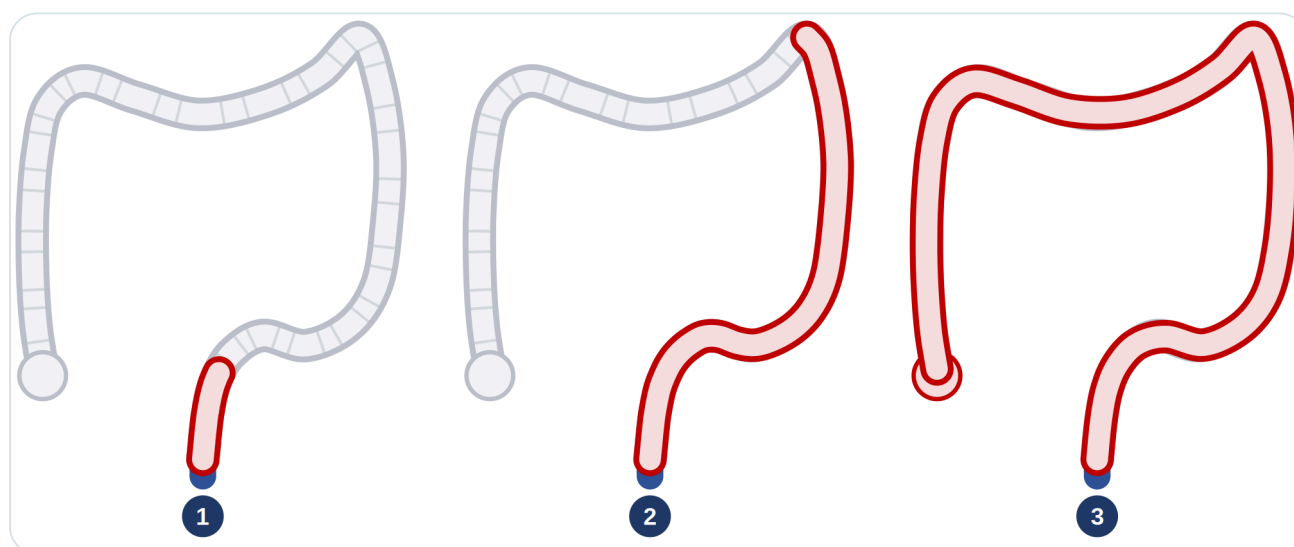
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This sheet explains what ulcerative colitis is, how it is monitored, how it is treated, and when to contact your doctor. Please bring it with you to your clinic appointments.

What ulcerative colitis is

Ulcerative colitis is a long-term condition in which the immune system attacks the lining of the large bowel and causes inflammation and ulcers. Unlike Crohn's disease it affects only the large bowel, only the inner lining of the bowel wall, and it is continuous – it starts at the rectum and extends upwards for a variable distance without healthy patches in between.

Ulcerative colitis is not caused by anything you did or ate, and it is not infectious. A mix of inherited genes, the bacteria in the gut and environmental factors is thought to cause it. It cannot be cured with medicine, but for most people it can be well controlled, and people with colitis can generally expect to live a long life.



How far the inflammation extends: 1 Proctitis – the rectum only 2 Left-sided colitis – up to the splenic flexure 3 Extensive colitis – beyond the splenic flexure, up to the whole colon

Symptoms

- Diarrhoea with blood or mucus, and needing to rush to the toilet
- Opening the bowels more often, including at night
- Cramping pain, often in the lower left side, and a feeling of incomplete emptying
- Tiredness, weight loss and anaemia. With proctitis, constipation is also common.
- Problems outside the gut – joints, eyes, skin, liver and blood. About one in four people with colitis develop at least one joint, skin or eye problem of this kind.

Tests we use

Colonoscopy or flexible sigmoidoscopy with biopsies confirms the diagnosis, shows how far the inflammation extends and how severe it is, and excludes infection. Between endoscopies we follow you with blood tests and a stool test for faecal calprotectin, which measures inflammation in the bowel directly – see sheet [PE-IBD-03](#). Intestinal ultrasound can also be used in clinic. A stool sample to exclude infection is sent whenever symptoms flare, because gut infections can look exactly like a flare.

Treatment

Treatment depends on how far the inflammation extends and how severe it is. Mesalazine and the other 5-ASA medicines are the mainstay for mild to moderate disease, and they work both to settle a flare and to keep it settled. For disease in the rectum a suppository is used, and for left-sided disease an enema or foam, usually together with mesalazine tablets – treatment given directly into the rectum works better than tablets alone. Steroids are added for flares that do not settle. If flares keep returning, or you cannot come off steroids, we use azathioprine or a biologic or advanced medicine such as infliximab, adalimumab, vedolizumab, ustekinumab, risankizumab, guselkumab or a JAK inhibitor. Each of these has its own information sheet.

Severe colitis – more than six bloody stools a day together with a temperature above 37.8°C, a pulse over 90, anaemia or a high CRP – needs admission to hospital for intravenous steroids, not an outpatient appointment. If there is not enough improvement within about three days we move quickly to rescue treatment or surgery.

The aim of treatment is that you have no more than three stools a day with no bleeding, and no inflammation visible at colonoscopy. Feeling better is not by itself

enough, because symptoms and inflammation do not always match.

Surgery

Around seven in every hundred people with colitis need surgery to remove the colon in the first five years after diagnosis, and about ten in a hundred within ten years. The colon may be removed with a permanent or temporary stoma, or an internal pouch (an ileo-anal pouch) may be formed later from the small bowel and joined to the anus. Removing the colon and rectum cures the colitis and removes the risk of bowel cancer. About half of people with a pouch get inflammation in it (pouchitis) at some point, which is usually treated with antibiotics. If you are a woman considering pouch surgery and may want children, discuss this with us first, as the operation can affect fertility.

Smoking

Ulcerative colitis is more common in people who have never smoked or who have recently stopped, and some people have a flare after stopping. This is a real finding, but it is not a reason to smoke: it is not clear what smoking does once you already have colitis, and the harms of smoking far outweigh any possible benefit. Guidelines advise people with ulcerative colitis not to smoke.

Bowel cancer and surveillance

Ulcerative colitis raises the risk of bowel cancer, but much less than older figures suggested, and the excess risk has fallen considerably. Across inflammatory bowel disease affecting the colon, roughly one in a hundred people develop bowel cancer by ten years after symptoms started, about two in a hundred by twenty years, and about five in a hundred beyond that. Keeping the inflammation controlled lowers this risk. We offer surveillance colonoscopy from eight years after your symptoms began – from the time of diagnosis if you also have primary sclerosing cholangitis – at an interval based on your own risk. Colitis limited to the rectum does not need surveillance.

When to contact your doctor

Symptom	What to do

Blood or mucus in the stool for more than three days, or a clear increase in stool frequency	Contact the IBD clinic
Waking at night to open your bowels, or new abdominal pain	Contact the IBD clinic
More than six bloody stools a day, or fever with a fast pulse	Same day – this may be a severe flare needing admission
Fever above 38°C while on medicine that affects the immune system	Same day – contact your doctor or attend the Emergency Department
Heavy bleeding from the back passage that does not stop	Emergency Department
Severe abdominal pain with a swollen, tender abdomen	Emergency Department

During a flare your mesalazine dose may be increased on our advice. Do not increase or stop your other medicines, such as azathioprine or a biologic, without speaking to us first.

How to contact your doctor

Contact your doctor during working hours, using the numbers your clinic has given you, for anything that is not an emergency – a reaction to a medicine, symptoms that are changing, a question about your treatment, or a repeat prescription. Tell your doctor about any reaction to a medicine: that is what lets your doctor bring your appointment forward. Routine blood tests can be done and reviewed at your local health centre – you do not need to wait for us for that. If you are seriously unwell, go to the Emergency Department rather than waiting for a reply.

Living with ulcerative colitis

There is no clear evidence that any particular food causes, cures or treats the inflammation in colitis; aim for a balanced diet and adequate fluids, and ask to see the dietitian if you are losing weight or avoiding many foods. Anti-inflammatory painkillers such as ibuprofen and diclofenac can trigger a flare – use paracetamol

instead unless we have advised otherwise. Tell your doctor if the condition is affecting your mood or sleep, as help is available. If you are planning a pregnancy, tell your doctor before you conceive; we aim for the disease to be settled for three to six months first, and most colitis medicines are continued through pregnancy and breastfeeding. Vaccination advice is in sheet [PE-IBD-04](#).

Contact your doctor using the numbers your clinic has given you. If you are seriously unwell, or it is outside working hours, go to the Emergency Department rather than waiting for a reply. This sheet is general information and does not replace the advice of your own doctor.
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